UNITED STATES ARMY CHAPLAIN CENTER AND SCHOOL

THE CHAPLAIN AND THE FAMILY WITH AN EXCEPTIONAL CHILD

RESEARCH PAPER REQUIREMENT
CREATIVE WRITING
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STATEN ISLAND, NEW YORK
FEBRUARY 1975

One of the groups of people on an Army base that is not noticed very much is the family with an exceptional child. This is not so true for the family where the child's difference is a physical one requiring braces, crutches or a wheelchair because of the obvious visability of the problem. The family with an exceptional child who has a problem that is not physically obvious is likely to be known only by their immediate neighbors, and they may not even know very much about the child.

Parents can be ashamed that their child is different, and so they say little to anyone about it and try to keep it secret. The tragedy here is that day by day the burden gets harder and harder on them to live with their family situation. We are not talking about a small or statistically insignificant portion of the community either. Selle states that about three percent of the population of the United States is affected in the area of mental retardation: "Nationally there are 6½ million, a gathering that would match the combined population of Los Angeles and Chicago."[1]

Exceptional children are not limited to the mentally retarded. Ellingson speaks of the prevalence of children with specific learning disabilities: "A widely accepted minimum figure is that ten percent of all school age children, of normal or above intelligence, fall into the general category of reading re-

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[1] Robert Selle, What Do You Say to Parents of a Mentally Retarded Child?, Pool of Bethesda Series, Bulletin IV (Watertown, Wisconsin: Bethesda Lutheran Home, 1974), p. 7.

tardation due to genetic dyslexia."[2] There are other kinds of exceptional children as we shall see later. Here we establish there is a significant number of exceptional children in our society; children who are exceptional for many reasons, not just mental retardation.

If we accept this premise, it is reasonable to assume we could find significant numbers of families on an Army post who have exceptional children. Out of the present C-22 class at the U.S. Army Chaplain Center and School there are at least six families who have an exceptional child.[3] This is approximately six percent of the families if you count each single student as a family unit. If single students are not each counted as a family unit the percentage is much higher!

This fact alone indicates that familiarization and awareness of these families with potential problems of adjustment and life style would be helpful to the Army Chaplain in his ministry to all people on his post. Even more evidence is available which indicates that this C-22 class is not something unique in having exceptional children. The Army Times tells of a program in effect at Fort Riley, Kansas to find exceptional children through a screening process developed in a cooperative program by the occupationaly therapy section of Irwin Army Hospital and the Geary County elementary schools on post. That screening has produced the

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[2] Careth Ellingson, The Shadow Children(Chicago: Topaz Books, 1967), p. 18.

[3] Names available if requested.

following results: "Sixty children between the ages of 3 and 11 participate in 45 minute weekly sessions, and another 80 are involved in follow-up testing."[4] One hundred forty children on one post! And this does not include any screening for pre-school children. Indeed, the area of concern regarding the exceptional child and his family is one the chaplain ought be aware of. He can be of great assistance at the very beginning--when a child is diagnosed as exceptional for whatever reason. His best assistance is that of bringing the love of God to that family, but to bring the message effectively, he needs to know some of the parental reactions and attitudes regarding the exceptional child, and also some knowledge of the educational opportunities for such children. With this background he can devise means by which the chapel program can be of real substantive help.

We assume that parents want what is best for their children. One of the things normally desired is a good education so the child might cope well with life. When a child is born the parents have many hopes and expectations for him. Surely it is a crushing emotional blow when it becomes apparent to them that something is different about their child, and their hopes and expectations turn to anxiety and fear. Whether that happens at the time of birth from an obvious birth defect or happens later on in the child's life is not at issue. Whenever a child is "different" the parents, if they have any love for the child at all, experience a reaction.

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[4] "Riley Clinic Solves Learning Disabilities", Army Times, 25 December 1974, p. 22.

I believe the degree of the reaction they experience is directly related to how much of the child's disability is obvious.

In an obviously retarded or physically handicapped child, the parents will go through the process leading to acceptance more quickly than the parents of a child with relatively minor problems. For the latter it is slower because it takes longer to admit the child has a problem. Whether this reaction process is done quickly or slowly is not that important to recognize. What is important is the realization that all parents of exceptional children go through it.

Anxiety strikes at the parents of a child who will be determined to be exceptional, "when they suspect or are informed that their child is not developing normally."[5] When this kind of news is received the parents are led to seek advice and counsel to determine just what is happening to their child. Buckler feels that a good diagnosis of a suspected mentally retarded or learning disability afflicted child should include a study of the family history as well as the history of the child; a general medical examination; physical testing to indicate muscular development; a complete neurological examination to test the responses of the brain and the spinal cord; speech, hearing, and vision tests should be given; and there should be complete psychological and psychiatric tests to cover not only the intelligence quotient, but also social development, emotional aspects and a

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[5] Samuel A. Kirk, You and Your Retarded Child (New York: The Macmillan Company, 1958), p.1.

total overview of the personality. [6]

Once testing has established that the child does have a real problem, parental reaction to the news becomes the immediate area of concern. Trapp notes a similarity between reaction to the diagnosis of retardation, and reaction to bereavement. [7]

Dr. Elisabeth Kübler-Ross in On Death and Dying indicates the stages a terminally ill patient goes through: 1)denial and isolation; 2) anger; 3) bargaining; 4) depression; 5) acceptance. [8] The relatives of a dead person go through the same process upon the death. If the deceased was terminally ill, the family tends not to begin the process until death takes place. Before that they stay pretty much in the denial or the bargaining stage. So even with advance warning that death of a loved one will come soon, it is hard to prepare for the grief process.

In similar fashion, parents cannot prepare in advance for what their reaction might be if they were to have an exceptional child. It must be faced when it happens, not in advance.

Trapp's observation of the similarity of reaction to a diagnosis of an exceptional child and reaction to grief upon the death of a loved one is supported by French. He indicates that one of the first parental defensive reactions to this kind

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[6]Beatrice Buckler, Living With A Mentally Retarded Child (New York: Hawthorn Books, Inc., 1971),pp. 17-18.

[7]Philip E. Trapp & Philip Himelstein, eds.,The Exceptional Child(New York:Appleton-Century-Crofts, Inc., 1962), p.237.

[8]Elisabeth Kübler-Ross, On Death and Dying(New York: Macmillan Publishing Co., Inc., 1969), pp. 38-137.

of diagnosis is denial, a refusal to admit that anything is wrong.[9] This agrees with Kubler-Ross' statement that the first stage of grief is denial as mentioned above. Buckler is a little more explicit: "...confusion, shock, grief, and even anger overwhelmed the parents...Why should they, of all people, have a retarded child?"[10] Kirk states that, "interviews with many parents have revealed a tendency to progress through stages of shock, disbelief, and fear and frustration before they finally arrive at the level of intelligent inquiry.[11] So there is indeed similarity in the reactions of the parents of exceptional children to the grief reaction.

I believe it is now necessary to consider the issue of guilt. The parents of the exceptional child go through a guilt stage; often it is an expression of the great anger they feel. But that anger may not be outwardly directed toward the school and teacher(or whoever made the determination regarding the child); more likely it will be directed at other family members, or it can be turned inward toward the self. All of these produce unhappy results.

Ellingson believes that the first step the parents of an exceptional child should take is "complete acceptance of the child and his handicap."[12] I believe this is not the first step parents

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[9] Edward L. French & J. Clifford Scott, Child in the Shadows(Philadelphia: J.B.Lippincott Company, 1960), p.22.

[10] Buckler, p. 1.

[11] Kirk, p. 2.

[12] Ellingson, p. 45.

take, but rather the last step, the conclusion of working through the process of grieving for what has happened to the child and to them. When this process has been completed, the parents can be enlisted to help the child significantly, but at first their preoccupation is with their own reactions. French bears this out in his discussion of the stages of parental development: 1) Why did this happen to me?(the stage of feeling sorry for oneself); 2)What can I do for my own child and for my family?(the stage of facing one's own problems); and 3) What can I do for others?(the stage of trying to help others in similar situations). [13] Once the parents have worked through the stage one they progress to stage two where they can be of real help to their child. Helping others comes later. I believe not all parents reach this stage, but it is certainly a worthy goal and would actually help the parents giving help as well as those receiving it. The chaplain can be of assistance here by being a facillitator for the family to work in stage three. We assume that he has been in continuing contact with the family from the time they learned of the child, or from the time he first learned of them.

When the parents ask the question "Why?" it tends to lead to guilt feelings on their part. Egg observes that parents when first told of their child's problems find little consolation in knowing that there may be many others with the same problem: "In the beginning, you may think that no other parents have been visited by such misfortune. That is why you feel shut-out of the

[13] French, p.130.

group of parents with normal children."[14] There is a tremendous feeling of anxiety that they have somehow done something wrong; the feeling persists that if only they had done something differently their child wouldn't have this problem. There have been, and continue to be, countless articles in newspapers and magazines, in novels, in "How to Raise Children" type books, and on television and radio talk shows that place too much emphasis on parental responsibility for how the child turns out. French speaks to this point and how it affects the parents and their guilt feelings:

> Indeed, it is now one of the most widespread myths in the field of child development that the child can be made into anything, depending on how his parents handle him...in other words, the theory goes, whatever a child's difficulties may be, they stem from some error on the part of the parents: from a failure to meet the child's needs, or a selfish sacrifice of the child to some parental ideal. Unfortunately, this theory has found a very receptive audience among parents themselves ...The parent feels, consciously or unconsciously, "This child is part of me; he belongs to me;whatever he is, I have made him--and if it is not good, I am to blame."[15]

So parents find themselves spending a lot of time on the question of why did it happen and who is responsible. Selle gives some most helpful advice to the pastoral counselor here: "Normal emotions only become abnormal when prolonged...the counselor 1) allows the reactions to be aired freely rather than internalized, and 2) shares the pain as one who weeps with those who weep..."[16]

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[14] Maria Egg, When A Child Is Different(New York:The John Day Company, 1964), p. 31.

[15] French, p. 19.

[16] Selle, p. 16.

How easy it is for this kind of stress from unnecessary feelings of guilt to turn husband against wife, each seeking to blame the other for "his" or "her" family. Ultimately, parents need to see that such pursuits are futile. Dr. Egg points to the reality which parents need to hear: "It does not really matter whether or not you find a reason for your child's mental retardation. Even if you did, this would not change anything in your child's condition." [17] French echos this opinion: "...there is really not guilt or culpability involved; that the sense of shame, guilt and desperation is not linked realistically to the child or his problem."[18]

How easy it would be for the counselor of parents or the teacher of the exceptional child to drive parents into the guilt trap, to have them search their lives for mistakes, to aid and abet their already present feelings of guilt and shame about their child. Just as we have already noted that the pastoral counselor will help the family get rid of its guilt trip, so we see French making the same point for other folk who deal with parents:

> It is the task of the professional not to condemn the parents for their fears, their angers, their refusal to accept facts, their initial rejection of the child, but to give the help that the parents want and need to grow beyond the pain, the guilt, the anxiety--to accept the challenge of their retarded child. [19]

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[17] Egg, p. 37.

[18] French, p. 21.

[19] Ibid.

Ellingson emphasizes much the same point, namely that the parents need not be guilty or remorseful: "Remember," he says, "it is not the end of the world for you or your child--in fact, the discovery is likely to turn out to be the beginning of a new world for you both."[20]

It can be a new world indeed as the parents focus their attention on helping the child instead of looking only at themselves. This will make life much easier for the child, for he often is aware that he has problems and that he is different from other children. This is certainly true for those with specific learning disabilities. The child is a person, and he comes to understand what is going on around him. He understands that his parents are upset with him, but he may not always know why. He understands that he is somehow at fault, which then discourages him from trying to understand what his folks want him to learn, which in turn produces more anxiety in him until a horrible circle of events encompasses him. Ellingson says it well:

> A dyslexic is intelligent and knows that he is an object of ridicule by other children, his ego is battered by failure at school, and he is aware that his parents feel frustrated and heart-broken because of his inability to achieve.[21]

How much of a new world it will be for such a child when he does not have to feel guilty and less than worthwhile, especially with his parents! When all the feelings about the child's problems

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[20] Ellingson, p. 96.

[21] Ibid., p. 17.

have been worked through by the parents, they are free to relate to him in a helpful way. When the child knows that he is accepted and loved, not for what he may be someday, but for what he is now, his motivation toward learning and living will be enhanced because he does not have to waste emotional energy on anxiety. Parental understanding helps remove the large aspect of fear from the life of an exceptional child. This is underscored in Trapp's book:

> Because it is learned, the subject's attitude towards a task(motivation) probably reflects attitudes of others towards the child, notably the attitudes of his parents...Where the parental attitude was most realistic, the child seemed best able to work out his realistic evaluation of his limitations and maintain healthy relationships. [22]

It is very human and understandable that parents will pass through various stages in coming to terms with the situation they face with an exceptional child in their family. This achievement is at no small emotional cost. Yet this must be done for the sake of the child. Gallagher underlines this: "...until all parents seek and accept in an objective and unemotional fashion this sort of advice and information(diagnosis of their child's condition), many youngsters will be deprived of help and understanding." [23]

French summarizes the need for parental acceptance of the exceptional child very clearly:

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[22] Trapp, pp.515-516.

[23] J.Rosewell Gallagher, "Can't Spell, Can't Read," Atlantic Monthly, 1948, Reprint #2 by permission, p. 5.

> That most parents twist and turn emotionally in an initial attempt to deny the situation with which they are faced is not surprising; what is surprising is that they eventually work their way through their own shock and respond to the need of their child. [24]

When the parents of the exceptional child have reached this point they become more involved in the reality of life for their child, and they begin to focus upon his educational needs. They turn to the schools, the teachers and counselors, and they turn to the chaplain and the chapel. It is a big step for a parent to say to another person "I need your help for my child." Chaplains and educators need to realize this and show understanding toward the parent. To be of help to them, the parents must be seen by the professionals as a positive force in helping their own child, and not just someone to be placated. If the parents are not actively involved in the education process, be it secular or religious education, they are making the learning process more difficult for the exceptional child than it need be. This would be because the parents would not understand what was being attempted, and because of lack of information and involvement they may be a resistant force rather than a constructive one. Ellingson agrees:

> No matter what the problem may be, the remedial facility must always have supportive help from the home environment. If the child has to fight his parents, as well as his problems, he is wasting strength in non-productive activity. [25]

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[24] French, p. 21.

[25] Ellingson, p. 55.

Gardener suggests that fancy or judgmental language not be used by the educator to impress the parents with his wisdom: "They do not need generalities about being a good parent. They do need specfic, concrete and practical suggestions about how they can best promote optimal adjustment for their child."[26]

Reger underscores the same point:

> Teachers should be able to talk with parents in language the parents can understand... (they) should stay close to topics directly related to the child when talking with the parents; these topics should be discussed in plain English with an awareness of the need for tact. [27]

Some don'ts are, or need to be, a part of the pastoral counselor's awareness. Pastor Selle suggests the following:

> Don't pity.
> Don't patronize. Parents may know more about mental retardation than you do.
> Don't give the impression that professionals have all the answers.
> Don't quote(as one pastor did):"Visiting the iniquity of the fathers upon the children...unto the third and to the fourth generation."(Exodus 34:7).
> Don't hold out unrealistic hopes:"He may someday be normal, etc."
> Don't expect things to happen overnight.
> Don't fake it. [28]

Most parents of the exceptional child love him and they care a great deal about what is happening in his education. When the educators and chaplains have the parents participate in the

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[26]William L. Gardner, Children with Learning and Behavior Problems(Boston: Allyn and Bacon, Inc., 1974), p. 316.

[27]Roger Reger, Wedy Schroeder, Kathie Uschold, Special Education(New York: Oxford University Press, 1968), p.60.

[28]Selle, p. 13.

secular and religious education plans for the child they will have an easier time with the child in the educative process because they will then have parental support and understanding in what they are doing instead of parental resistance. Teachers are very great authority figures in the life of the child. This is true not just for public school teachers, but also for Sunday School teachers. But parents are great authority figures in the child's life, and they spend more time(hopefully!) with the child than the teacher does. If the parent does not understand what the teacher is doing and makes negative comments about the teacher and what is happening at school or chapel, the child is faced with the immediate conflict of choosing between his teacher or his parents. It is better to avoid the necessity for such a choice by the child. The parents do not wish to be kept in the dark wondering what the teacher will do next. They wish to participate in a positive and constructive manner in their child's learning process. Kirk indicates clearly his feeling that parents can be a constructive force in the education of the exceptional child, particularly the child with auditory problems of perception; with visual handicaps, and with the physically handicapped child.[29]

Needless to say, parents are not without their faults. Sometimes they are one of the causes of the problem a child faces. Kirk indicates that the child with a behavior disorder may behave in his disruptive fashion as a form of rebellion against parents

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[29] Samuel A. Kirk, Educating Exceptional Children, 2d edition(Boston:Houghton Mifflin Co.,1972), p.260,p.343, p.382.

who ask too much by demanding achievement beyond the child's capacity.[30]

Parents can be a cause of a child's stuttering by making an incorrect assumption that because a child is slow getting his words out that he is a stutterer, and so they become fearful and anxious. The child picks up the anxiety of his folks and when called on to speak, he "hastens to get the words out before he is reproved, thus continuing the cycle of fear-anxiety-non-fluency. The stuttering of the child, then, is initially something in the mind of the parent."[31]

When this kind of activity on their part is pointed out to them in terms of the disruptive result it has on their child, most parents will modify their behavior to help their child. It would be an unloving act for the parents to continue the behavior which causes the child problems. I am sure there are such sadists, but they are beyond the scope of this paper, unless the chaplain or counselor can reach them to help them change.

Parents can learn what mistakes they are making from the educators; it is part of the process of working together. The opposite is also true. Religious and secular educators can also learn from the parents what the parents feel to be mistakes. Maybe they are mistakes, and then the education program can be modified. Perhaps they are not educational mistakes. This then is a

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[30] Ibid., p. 397.

[31] Ibid., p. 89.

marvelous opportunity for the educators to share what they are doing and why and so promote parental understanding.

The important thing is to reach mutual cooperation between parents and educators. When this is reached, an approach to the child's education or training can be established. One of the tools at hand for this is the result of all the testing that led to the initial diagnosis of the child's problem. Those test results give the educator his base for an educational approach to the problem of that individual child. Buckler states the importance of establishing an educational approach: "No matter what the degree of retardation or what special needs a child may have, an objective and a program are essential. Having a program makes an undeniable burden manageable."[32]

The chaplain or religious educator would do well at this point to seek the cooperation of the parents and secular educators to determine the program or approach for each child so that the religious education of the child can fit in with the program and not be counter-productive. Since secular educators tend to be somewhat secretive about such records parental cooperation is essential. A new law was signed and implemented federally in 1974. This law, the Family Educational Rights and Privacy Act of 1974, protects the privacy of student's records and guarantees the right of the parent to review them. The law specifies: "Records may not be sent to any person or organization unless there is written consent from the student's parents...If the parents...

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[32]Buckler, p. 3.

desire they shall be given a copy of the records."[33] So if the step need be taken the parents can invoke this law and secure the records of their own child for use by the chaplain and the religious educators. It would be best if this extreme step were not necessary. Now it is available if needed.

It is much better for all concerned, and most of all better for the child, if the goal is set so that all can work toward it: the child, the parents, the school and the religious educator or chaplain.

One thing that I could not find in the literature, but which I believe most necessary if the educational approach is going to be as effective as possible in motivating all concerned, is the provision of measurable points of achievement. There needs to be a method of feedback to check progress, and to help tailor and re-tailor as needed the program or approach for maximum effectiveness.

So parents will look to the school with its professionals for help; they will look for community resources also. Hopefully many parents will turn to their chapel for help too. Buckler points out that parents have the right to expect professional help from the schools and other community resources.[34] He doesn't mention the church, but the parents have the right to expect church, chapel and chaplain involvement if they desire it.

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[33] Myron B. Unger, "Law Guarantees Privacy of a Student's Records"Staten Island Advance, 7 October 1974, p.6.

[34] Buckler, p. 60.

At the same time, it must be established, it would be a mistake if the parents were to feel the school or community agency or church or chapel would do it all. Any education or training program for the exceptional child is going to take a lot of time, a lot of involvement, and a lot of love. That parental love will motivate most parents to be effective partners on the education team, not just by agreeing with what others are doing, but also by providing learning experiences at home that are co-ordinated with the school, chapel or agency effort. Gardener says, "Parents frequently are quite eager and capable of providing more (i.e. additional) appropriate learning experiences in the home for the young child with problems."[35] The professionals can carry on alone if they must, but when the home is involved it is better for the child. He will learn faster, and he will be supported as he faces his problem. Involvement in the home will show the child that his disability is not being ignored, that he counts in the family, and that his parents care for him just the same despite the disability. Ellingson points out an appropriate approach at home: "Excess tension will not help; warm understanding and frank discussion of the problem at a level appropriate to the child's age, will."[36] French speaks to this same point in his positive view toward parents as helpful in the education of the child at home as well as school. Regarding these, "active

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[35] Gardener, p. 315.

[36] Ellingson, p. 44.

participants...of primary importance is their readiness to accept the child as he is--to give him a feeling of belonging, without the necessity for his striving to achieve beyond his ability."[37]

We have seen that the attitude of the parents has a tremendous impact on the exceptional child. They have a lot of work to do at first when their child is diagnosed as having a problem. Here the chaplain, if is knows of the situation, or is called in, can be of great help in bringing the consolation of the Word of God. His ministry and the knowledge of God's love for them and for their child can help the parents work through their anxiety, their fears, their feelings of guilt and anger as quickly as possible so they reach the point where they can accept their child and his handicap fully and completely, and so are ready to be a positive force in their child's development.

The parents' work at the task of helping their exceptional child learn to become a responsible and functioning member of society, and at helping him to know of God's love in his life, is not easy, and it doesn't have a termination point; it is ongoing. Dr. Egg points this out so well in her beautiful and sympathetic approach to parents:

> Your attitude will have a decisive effect on the entire family; the mood of a home depends on the parents. They give peace and joy to a home. But you can only give what you have. This means that there must be an inner peace within both of you. But this inner peace is not a

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[37] French, p. 87.

gift. You must work hard for it.[38]

The hoped for result of the parental reaction process which begins when parents are informed that their child is an exceptional child is the parents and educators, both secular and religious, in partnership working on a specific educational approach or program to help the child to achieve his appropriate place as a productive member of society if possible, and to know God's love for him.

The chaplain can provide help in many ways for families with exceptional children. First, he offers himself together with the words of God's love. He helps the family through its time of travail. Other things he might do could include calling together several families with exceptional children--that in the sharing of common or similar problems they tend to give strength to one another. He can use all resources at hand in cooperation with the parents to provide religious education classes for these exceptional children, but at the same time insuring they are an integral part of the chapel family. He can encourage the members of the chapel families to be accepting of these people with troubles; the healing touch of the People of God is immeasurable. He can encourage members of the chapel family to help with some of the physical chores that these families face. Even teens can help beautifully by baby-sitting, and giving mom and dad a chance to be on their own for a time. Volunteers from the chapel can be encouraged to work at nearby facilities. He can encourage regular visitation to the

[38] Egg, p. 45.

homes of exceptional children by members of the chapel family, so that the parents of these children will know acceptance. [39]

We conclude with this statement of Pastor Selle who says it better than I can:

> A pastor who has worked for years with the retarded had this to say:"It's so easy to get hung up on statistical returns, to rationalize spending the most time on those who can memorize and recite the Creed, the Lord's Prayer, who can learn simple Bible stories...and then in the case of SEVERE retardates to say,'all they need is baptism and our intercessory prayers.' Where in that attitude is the trust of a mother who sings 'Jesus Loves Me' to her week-old baby, in full confidence that the child is growing in God even though he is nonverbal and lacks accountability? Just WATCH a new mother sometime. She doesn't wait until her son can formulate a syllogism before she talks, sings and loves God into his tiny life. God works in mysterious ways that are surely beyond our comprehension." [40]

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[39] Selle, pp. 24-25

[40] Ibid., p. 28.

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